Implementing specialist psychological support for caregivers in psychosis services:

A preliminary report

Short title: SUPPORTING CAREGIVERS IN PSYCHOSIS SERVICES

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Abstract

Background: Research demonstrates the importance of supporting caregivers of people with psychosis, but routine implementation studies are lacking. We evaluate a newly-developed caregiver support service, offering individual and group psychoeducation, practical advice and emotional support, working alongside usual community mental health provision for people with established psychosis.

Aims: We aimed to provide analysis of preliminary data on the rate and suitability of referrals, engagement, and helpfulness, to inform future larger-scale implementation and evaluation.

Method: We conducted a mixed-methods audit during the service's first ten operational months (01/09/2013 to 30/06/2014). Caregivers gave qualitative feedback and completed measures of the impact of caregiving pre- and post-intervention.

Results: Referrals totalled 103 (10/month), with 45 (44%) initial meetings; and 28 (27%) individual interventions (≥1 sessions, mode=3). Caregivers were predominantly black British/African/Caribbean parents. Self-reported needs and caregiving experiences were consistent with the literature. Two-thirds of caregivers were clinically distressed. Qualitative feedback showed that caregivers valued the service. Outcomes suggest improved experiences of caregiving following intervention.

Conclusions: Findings highlight the potential benefits and challenges of routinely providing psychologically-focused caregiver support. Limitations and future plans are discussed.

1. **Introduction**

1.1 Background

Psychosis is characterised by hallucinations, delusions, disorganisation, and unusual behaviour, which typically attract schizophrenia-spectrum diagnoses, but also occur in mood and some personality disorders (Cowen, Harrison, & Burns, 2012). Psychosis can be debilitating, requiring long-term care, and, given the increasing emphasis on non-residential services, shorter hospital stays, and disinvestment in community mental health provision, unpaid 'informal' caregivers are increasingly relied upon to provide on-going support (Askey, Holmshaw, Gamble, & Gray, 2009; Docherty & Thornicroft, 2015).

The impact upon caregivers of providing support, their consequent needs, and the historical lack of provision to meet these needs, are all well-documented (Kuipers, 2010). Caregivers typically highlight practical needs: more information about psychosis, including crisis management; and greater involvement in care-planning (Askey et al., 2009; McCann, Lubman, & Clark, 2011; 2012). Less commonly self-reported needs include coping with repeated exposure to traumatic situations and unpredictable behaviour (Kuipers, 2010), isolation (Hayes, Hawthorn, Farhall, O'Hanlan, & Harvey, 2015), stigmatisation (Corrigan & Miller, 2004), and depression, anxiety, and physical health problems (Gupta, Isherwood, Jones, & Van Impe, 2015).

The latest United Kingdom National Institute for Health and Care Excellence guidance for the treatment of adults with psychosis advises mental health services to develop caregiver care plans to meet assessed needs, provide information, offer support, and include caregivers in decision-making whenever possible (NICE, 2014), consistent with policy

recommendations and expert calls for specialist, caregiver-focused support services (Carers Trust, 2013; Kuipers, 2010). To date, interventions for psychosis caregivers have been limited to short-term pilot and research projects (e.g. Chien, Thompson, Lubman, & McCann, 2016; Lowenstein, Butler, & Ashcroft, 2010; McCann et al., 2013; Roddy, Onwumere, & Kuipers, 2014); knowledge regarding the feasibility and helpfulness of implementation in routine care is limited.

In response to NICE guidance, we have developed a new Carer Support Service (CSS), offered routinely to informal caregivers of individuals receiving community mental health care for established psychosis (Smallwood, 2016). The service is based in the South London and Maudsley National Health Service (NHS) Foundation Trust (SLaM), in the densely populated, ethnically diverse, socially and economically deprived inner-city boroughs of Lambeth and Southwark, with high rates of unemployment, crime, and psychosis (Kirkbride et al., 2013; Lambeth Council, 2014; Southwark Council, 2014). Given the nature of psychosis and the complexities of caregiving, and the reported challenges of engaging this particular population of caregivers despite their significant needs (Szmukler et al., 2003), the service was designed to flexibly accommodate varying levels of engagement and need for support, working closely with the boroughs' community mental health teams (CMHTs). Caregivers were offered a stepped model of telephone, face-to-face, group, and individual support (Figure 1). The CSS also facilitated communication and shared care-planning with the CMHTs, interfacing with local, generic carer organisations, and with CMHT family intervention specialists. Individual support comprised brief, personalised psychological interventions, found to be helpful for caregivers in this population (Roddy et al., 2014).

1.2 Aims

We outline our service model and evaluate its implementation in Lambeth, the first of the two boroughs to offer the CSS, auditing the rate and characteristics of referrals, engagement and outcomes during the first ten operational months. Caregivers completed measures of the impact of caregiving pre- and post-intervention and gave qualitative feedback.

Our evaluation questions were:

1) Do the rate and throughput of referrals indicate manageable demand?
2) Do referrals reflect needs potentially addressed by NICE-recommended caregiver support?
3) What are the levels and patterns of engagement?
4) Do caregivers benefit from engaging?

We aimed to provide analysis of preliminary data to inform future routine implementation and evaluation of caregiver support recommendations.

2. Method

2.1 Service context and staffing

The Lambeth CSS covers five CMHTs, each providing treatment for 200-250 working-age adults with established psychosis. Research and local service data suggests that approximately one third of service users have a caregiver (Kuipers, 2010). Local NICE implementation funding supported the appointment of two half-time Carer Support Workers (CSWs), with undergraduate psychology, but no professional mental health, qualifications. Supervision, governance and training is provided by clinical psychologists with expertise in working with people with psychosis and their caregivers.

2.2 Referral routes and inclusion criteria

The CSS is open to relatives and friends in close contact with service users treated by the CMHTs, without caregiver-specific exclusion criteria, whether or not they consider themselves to be a 'carer'/'caregiver'. CSWs liaised with teams to elicit referrals (brief details of service users, with caregiver name(s) and contact details). Caregivers could also self-refer.

2.3 Interventions

Interventions (Figure 1) were offered cumulatively. All caregivers were offered telephone support, an initial meeting, and groups providing information/psychoeducation and facilitated peer discussion of caregiving experiences (Level 1). Caregivers attending an initial meeting were also offered Carers Needs Assessments (Level 2). Level 3 comprised brief (1-6 sessions of 30-60 minutes) psychological interventions including psychoeducation about psychosis, treatment and management; improving communication; problem solving; and care/crisis planning (jointly with the CMHT and service user as indicated). Emotional issues impacting on caregiving relationships in psychosis were also addressed, most commonly, grief, loss, and guilt. Caregivers were referred to appropriate community services for financial, housing, or social care issues, and to CMHT specialists for family intervention.

Figure 1

2.4 Measures

Standardised Carers Needs Assessments (CNAs), following local health and social care guidelines, were delivered as structured interviews, assessing caregivers' understanding of

psychosis; the care they provided; and their support needs. Caregivers considering the brief psychological intervention were asked to complete psychological measures pre- and post-intervention:

1. *Distress:* the Clinical Outcomes in Routine Evaluation scale (CORE-10) assesses anxiety, depression, trauma, physical health symptoms, functioning and risk, across ten items rated from 0 to 4 (range: 0 (low) to 40 (high)), validated in general population (mean=4.7, standard deviation (SD)=4.8), primary and secondary care settings, with scores above 11 indicating clinical levels of distress (Barkham et al., 2012; Connell & Barkham, 2007).
2. *Mental wellbeing:* the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) measures positive mood, functioning and relationships, across 14 items rated from 1 to 5 (range: 14 (low) to 70 (high)), validated in the general population (mean=50.7, SD=8.8; Stewart-Brown & Janmohamed, 2008).
3. *Experience of caregiving:* the Experience of Caregiving Inventory (ECI, Szmukler et al., 1996) measures caregiving experiences across eight negative (difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need to back up, dependency, loss) and two positive (positive personal experiences, good aspects of the relationship) subscales. Respondents rate how often they have thought about each of 66 statements over the previous month, from 0 (never) to 4 (nearly always) generating total positive (0-56) and negative (0-208) scores. The ECI is designed for psychosis caregivers, with good face and construct validity (Joyce, Leese & Szmukler, 2000).

2.5 Procedure

We audited the first ten operational months of the service (Sept 2013-June 2014). Caregivers completed baseline measures routinely at entry to Level 3 of the service and post-intervention. Feedback questionnaires were completed after group meetings, and were posted after six months of operation to all caregivers who had accessed Level 3 interventions. Caregivers gave written informed consent for measures and feedback to be used pseudonymously for service evaluation; consent could be withdrawn at any time without reason or impact on service provision. The evaluation was approved by the Trust Audit and Evaluation Committee (reference PSYCHLO-14-27). Access to the CSS was not dependent upon completing measures or providing feedback. Trust interpretation services were available.

2.6 Analysis

Referral rate was calculated per month. Referral characteristics comprised service user demographics; caregiver-reported experience of caregiving; and caregiver-reported needs, identified by thematic analysis (Braun & Clarke, 2006) of the first ten (Sandelowski, 1995) completed CNAs. Engagement was assessed by intervention uptake and qualitative feedback, thematically analysed. Preliminary effect sizes (d) were calculated using the difference between pre- and post-intervention means, divided by the common standard deviation, for all available outcomes, and for paired outcomes only. Baseline severity of distress was established using the published clinical cut-off point for scores on the CORE-10 (Connell & Barkham, 2007); ECI scores were contextualised by scores from previous psychosis caregiver samples.

3. Results

3.1 Referral rate

Caregivers of 103 service users were referred (10 referrals/month: approximately 8-10% of the CMHT caseload; and 25-30% of caregivers). Around half of these attended an initial meeting, and a third engaged in individual intervention (Figure 2). Three information/support groups were attended by n=9; n=6; and n=8 caregivers, respectively.

3.2 Referral characteristics

Caregivers were predominantly parents of sons with a schizophrenia diagnosis, with an ethnic mix representing the local area (Table 1). Caregivers reported needing emotional and practical support and help to understand psychosis and manage relationships, both with the cared for person and their wider networks (Table 2). Scores on baseline measures indicated that caregivers were clinically distressed (Table 3).

Figure 2

Tables 1-3

3.3 Engagement

Rates of attendance (44% of referrals; 4-5% of the CMHT caseload) and engagement in intervention (27%; 2-3% of the CMHT caseload) indicate that over ten months, approximately 10-15% of eligible caregivers were seen, with 7-10% receiving an intervention. Attendance at individual meetings was irregular and often driven by immediate need: completing brief interventions frequently took several months (range: 1-12 months), with frequent cancellation and non-attendance.

Of 16 postal feedback forms, five (31%) were returned. Of 23 group feedback forms, 21 (91%) were returned. All respondents reported they would use the service again; 25/26 would recommend it to others. Qualitative feedback highlighted the importance of facilitating CMHT contact and collaborative care, and of flexible and accessible emotional and social support (Table 4).

Table 4

3.4 Intervention outcomes

Mean scores on assessment measures at baseline and post-intervention are shown in Table 3, with indicative group and paired pre-post effect sizes. Outcomes suggest small improvements in wellbeing, and larger improvements in caregiving experiences.

4. Discussion

We aimed to inform the future routine implementation and evaluation of interventions for caregivers of people with established psychosis by auditing our new community-based, inner-London specialist support service, over the first ten operational months. We considered referral rates and characteristics, engagement, and potential benefits to caregivers.

Close liaison with CMHTs was required to elicit referrals; referring was deliberately straightforward, to limit obstacles to access. Referrals represented approximately 8-10% of the CMHTs' caseload and an estimated 25-30% of caregivers, based on research and local service estimates of contact with informal caregivers in established psychosis (Kuipers, 2010). This suggests that over three years, all caregivers would be offered support. The service saw approximately 10-15% of eligible carers, with 7-10% receiving an intervention, over the ten month period. The referral rate (average 10/month) was manageable with the

available staffing and generated average Level 2 caseloads of 4-5/month, and 2-3 new Level 3 cases/month. Level 1 contact was continued with all referrals, unless specifically declined (n=9).

The caregivers referred represented the local service population in their ethnicity and the characteristics of those they cared for (high rates of psychiatric admissions, substance use, and involvement with criminal justice services), suggesting equitable access. Caregivers were distressed, with caregiving experiences and needs comparable to early and acute psychosis caregiver populations (e.g. McCann et al., 2011; 2012; Szmukler et al., 1996). Caregivers therefore appeared to be sufficiently similar to those participating in research contributing to the NICE guidance recommendations to potentially benefit from the recommended interventions.

Only around a tenth of caregivers declined support, indicating the acceptability of, and need for, the service. Of the remaining 90%, around half progressed to Level 2 and a third to Level 3. Caregivers not receiving, or having completed, Level 2 or 3 interventions remained on the caseload for occasional contact and group invitations. Cancelled appointments were common and staff working patterns were flexible to avoid wasted time. Contact tended to be driven by periods of higher need. Group attendance suggested this was an acceptable and efficient intervention.

Feedback form completion following group attendance was good (91%, 20% of the total sample), and this is a promising method for future evaluation. Return of postal feedback was poorer (31%, 5% of the total sample): given the limitations of this survey method (Kelley, Clark, Brown, & Sitzia, 2003) we did not collect further postal feedback. Caregivers reported satisfaction with groups and, for the small number returning questionnaires, with individual

interventions. No caregiver commented adversely on CSWs' lack of a core mental health profession. Caregivers valued flexibility and sensitive but persistent outreach: maintaining telephone contact and group invitations encouraged engagement, and facilitated contact at later times of difficulty. Sharing experiences and ideas in groups was validating, normalising and promoted solidarity, consistent with previous studies (Lowenstein et al., 2010), but many caregivers preferred individual meetings to address complex emotional reactions and establish the detail necessary for effective crisis planning. Supporting caregivers through crises, relapses and re-admissions, and ensuring adequate service-user care when CMHTs were less aware of relapse indicators, was more common than anticipated. The stepped care approach otherwise worked well.

Baseline Level 3 outcomes completion was good (23/28, 82%). Just over a third of caregivers completing baseline measures completed follow-up outcomes (9/23, 39%). Preliminary findings are of greater change in caregiving experiences than distress and wellbeing, which may still be impacted by on-going caregiving responsibilities when service user recovery is limited (Szmukler et al. 2003). Further evaluation will require ≥300 referrals, to ensure ≥20 paired ECIs, for reliable detection of large effects (α=0.05; 80% power).

There are numerous methodological limitations. As an in-service audit, there was no selection or randomisation and outcomes are pre-post, and uncontrolled. Findings are service-specific, and may not generalise to non-urban or early intervention settings. The short timeframe covered service set-up: referral and engagement patterns may take time to establish. Although the CNA was apparently acceptable, a carer-constructed schedule may have highlighted other issues. The sample size for CNA analysis was determined by published recommendations and apparent theme-saturation, but interpretation is subjective (Joffe & Yardley, 2004). While we

consulted caregivers informally, we did not employ peer workers or formal co-production, which may improve engagement. Feedback and outcomes post-intervention were collected for small self-selecting subgroups, and may not be fully representative. Preliminary effect sizes were calculated from pre-post group means, and require confirmation. No feedback was received from caregivers who declined support or disengaged. Employing questionnaires, rather than focus groups, allowed private feedback, but limited opportunities to elaborate or clarify (Thomas, 2003). Several implementation issues were addressed in a small study: each requires further robust investigation to confidently inform future service delivery.

5. Clinical Implications

Findings support the feasibility and potential value of the service model, in meeting guideline recommendations for a relatively small investment. Flexibility, persistence and expertise are required to overcome engagement challenges. Larger-scale, longer term evaluation is ongoing.

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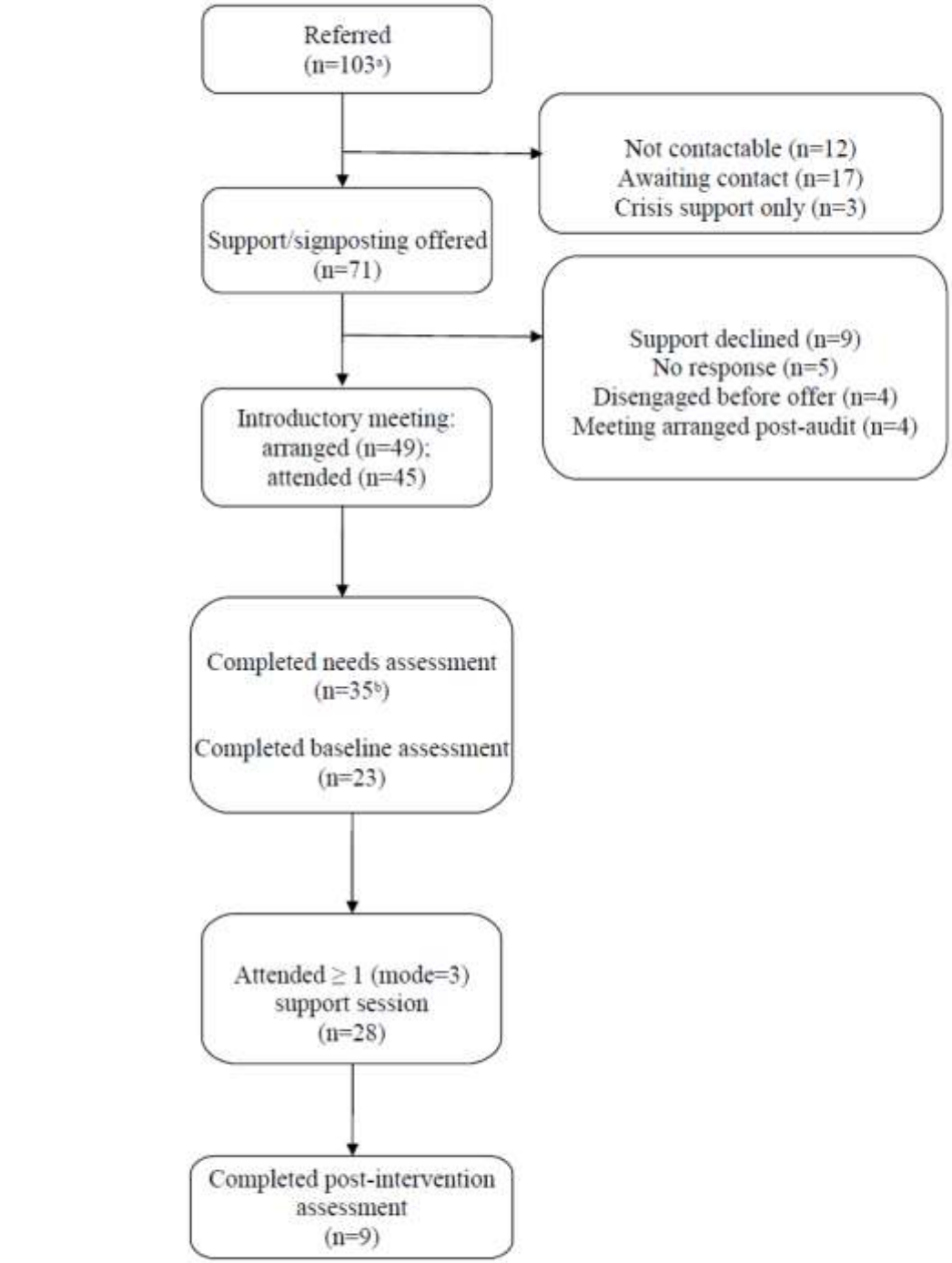
Figure 1: Stepped care model

Intervention Level (L)	Description
L1	• *Information/support groups* • *Telephone contact* • *Offering L2-4* • *Signposting/referral for social care, housing, financial needs*
L2	• *Initial meeting* • *Assessment of needs (informational/psychological)*
L3	• *Brief psychological intervention* *1-6 individual, 1-hour sessions, individually-tailored, needs-led.* *Includes: psychoeducation about psychosis and management; improving communication; problem solving; understanding unusual/difficult behaviour; boundary-setting; relapse prevention; self-care; counselling approach to strong emotional reactions impacting on caregiving relationship (commonly grief, loss, guilt).* • *Joint meetings, facilitating communication with services and service users.*
L4	• *Referral to family intervention with qualified therapists.*

Figure 2: Caregivers' progression through the service



[a]Main (most time face-to-face) caregiver reported for n=31 multiple-carer referrals. [b]n=4 declined needs assessment but attended support, n=1 declined both after initial meeting.

Table 1: Service user demographics (n=103)

Demographic		
Mean age (years)		40.6 (SD 13.24, Range 19-83)
		n (total n=103)
Relationship to main caregiver	Adult child	61
	Sibling	15
	Parent	13
	Partner/spouse	12
	Other	2
Living with caregiver	No	55
	Yes	48
Gender	Male	61
	Female	42
Ethnicity	Black (British, African, Caribbean)	62
	White (British, Irish, Other)	25
	Mixed heritage	8
	Other	8
Casenote diagnosis	Schizophrenia	72
	Bipolar affective disorder	10
	Schizoaffective disorder	10
	Other psychotic disorders	11
History of admission to psychiatric hospital	Yes	96
	No	7
History of problematic drug/alcohol use	Yes	50
	No	53
Forensic history	Yes	43
	No	60
Employment status	Unemployed	94
	In employment/education	9

Key: SD=standard deviation

Table 2: Carers Needs Assessments: themes compared to previous literature (n=10)

Previously reported caregiver needs				
Psychoeducation	**Practical advice**	**Difficult behaviours**	**Emotional reactions and isolation**	**Mental and physical health**
Study theme				
Understanding Psychosis	Practical support (self and/or service user)	Managing relationships	Emotional support (self)	Carer wellbeing
Study subtheme				
• *Psychotic symptoms* • *Dual diagnosis* • *Medication adherence* • *Risk, aggression and crisis*	• *Housing* • *Finance* • *Legal* • *Liaison with services* • *Employment support* • *Other activities*	• *Improving caregiving relationship* • *Improving other family/social relationships* • *Boundary-setting in caregiving relationship* • *Being assertive*	• *Negative emotions* • *Negative caregiving experience* • *Perceived stigma* • *Lacking a confidant* • *Neglecting own needs*	• *Physical health* • *Mental health* • *Family's health* • *Sleep problems*

Table 3: Routine outcomes at baseline and post-intervention.

Measure (Range)	**Baseline mean (SD)** (*n*=23)	**Follow-up mean (SD)** (*n*=9)	**Effect Size (d)** All/Paired only
Distress CORE-10 (0-40)	12.8 (6.6)	11.6 (7.8)	0.2/0.2
% scoring ≥11	61%	56%	
Wellbeing WEMWBS (14-70)	45.3 (10.6)	48.3 (13.2)[2]	0.2/0.3[2]
Caregiving experience ECI negative subscales (0-208)	93.0 (28.3)[1]	73.8 (27.2)[2]	0.7/0.9[3]

	Baseline caregiving experience: comparison samples. Mean (SD)			
ECI subscale	*Current* (*n=22*)	*Addington et al. (2005)*[a] (*n=185*)	*Szmukler et al. (1996)*[b] (*n=63*)	*Treasure et al. (2001)*[c] (*n=68*)
Stigma (0-20)	6.6 (5.4)	6.5 (4.9)	6.32 (4.8)	3.5 (4.0)
Problems with services (0-32)	7.5 (5.0)	10.8 (6.0)	11.24 (5.9)	8.5 (6.2)
Need to back-up (0-24)	13.0 (3.5)	9.9 (5.3)	10.31 (5.5)	8.5 (5.0)
Dependency (0-20)	13.5 (3.5)	10.4 (4.4)	10.52 (4.5)	7.9 (4.9)
Effects on family (0-28)	9.3 (6.4)	9.1 (5.6)	9.36 (5.9)	6.7 (5.1)
Loss (0-28)	14.5 (6.3)	12.6 (5.6)	12.53 (5.6)	8.6 (5.2)
Difficult behaviours (0-32)	15.1 (7.9)	13.4 (7.7)	13.85 (7.9)	7.7 (6.4)
Negative symptoms (0-24)	13.5 (5.8)	13.5 (6.1)	13.45 (6.2)	7.7 (6.5)
Negative subscales (0-208)	93.0 (28.3)	86.1 (32.5)	87.58 (33.6)	59.1 (32)
Good aspects of relationship (0-24)	14.6 (3.5)	14.2 (4.4)	14.05 (4.3)	12.3 (4.5)
Positive personal experiences (0-32)	16.0 (7.7)	15.8 (6.5)	15.8 (6.4)	14.1 (6.9)
Positive subscales (0-56)	30.6 (9.4)	30.0 (-)	29.85 (-)	26.4 (9.7)

Key: [1]n=22; [2]n=8; a=first episode psychosis; b=repeated admission; c=community-based. CORE-10=Clinical Outcomes in Routine Evaluation; WEMWBS=Warwick Edinburgh Mental Wellbeing Scale; ECI=Experience of Caregiving Inventory. SD=standard deviation.

Table 4: Caregiver feedback: thematic analysis (n=26).

Theme 1: Needs	
Subtheme	**Example quotes**
Services	• *"...X's case needs a lot of hard work to get X to recovery, co-operation from the staff and me and [CSW], and it is not easy work at all. It should be done as quick as possible before something bad happens"* • *"...underfunding has led to staff shortages and a lack of other resources... the whole system needs a radical overhaul to change attitudes and introduce common sense"*
Information	• *"I'd like to be made aware of any education /employment for the people we care for"* • *"If they are getting better and they want to go out to work, how can we encourage them[?]"*
Co-operation	• *"...to really help carers the service needs the power to implement action when it is clear another service is failing the patient"* • *"There should be strong co-operation from the team toward X's recovery... all of us should work together to get X out of the bad habit of taking alcohol and drugs"*
Theme 2: Psychological benefits	
Subtheme	**Example quotes**
Reduced distress	• *"[CSW] has provided a never-ending source of comfort and moral support"* • *"[You] understand what the carer is concerned about"*
Support	• *"[...useful to have] a mobile number so I can reach [CSW]"* • *"...having access to [CSW], either in person, by phone or by email very reassuring plus the fact that her brief was wide enough to include other members of the family"*
Coping	• *"...helped me with dealing with my anxieties"* • *"Regaining a sense of legitimacy of thoughts, feelings and time I try to claim to myself"*
Theme 3: Sharing	
Subtheme	**Example quotes**
Mutuality	• *"Sharing mutual experiences"* • *"Meeting other people with the same problems"*
Learning	• *"Sharing information and learning about other people's experiences as carers"* • *"Hearing other carers' concerns and experiences"*
Solidarity	• *"To have one's own experiences and perplexities mirrored in so many other carers' reports"* • *"[helpful] to know that I am not the only person going through the caring process"*

Key: CSW=Carer Support Worker; X = service user's name.